

APPENDIX XI

The 2003 RARE Project Findings

The 2003 RARE Project is an in-depth qualitative assessment of the HIV prevention needs of the African American and foreign-born Black communities in Seattle. Based in the Central District and the Rainier Valley, the assessment conducted ethnographic observation, interviews, focus groups, and street-intercept surveys with community members, service providers (HIV and non-HIV providers), and community leaders. Conducted by a team of field investigators who are themselves community members, these data collection methods yielded a wealth of information about the HIV prevention needs of this community. Because of the importance of the findings from this assessment, applicants for funding to serve African Americans and foreign-born Blacks in King County should incorporate the RARE findings as much as possible into their interventions. Below is a summary of the major findings. We strongly suggest that applicants who are applying for funds to reach these sub-populations contact Karen Hartfield or Barb Gamble at 296-4649 for more information.

Invisibility:

Even though HIV and AIDS disproportionately impacts African Americans and foreign-born Blacks in King County, members of the community feel they don't see information about the epidemic or HIV prevention education information (brochures, pamphlets, posters, advertisements, etc.) anywhere in their neighborhood. To make the epidemic more visible, and to normalize discussions of HIV prevention, more information should be available in a way that they cannot help but access. Many respondents suggested a media campaign similar to recent campaigns against smoking (for example, "It's the truth, it's an outrage").

Stigma and Fear:

Many community members see HIV as a death sentence. The disease, and those infected with HIV, are stigmatized because many view the risk behaviors as immoral. Respondents often characterized HIV as a gay disease and did not see themselves at risk. Even getting tested for HIV is seen as admitting to immoral behavior. Contracting HIV is seen as bringing shame on oneself, one's family, one's community, and one's church. To reduce the stigma and fear, a great deal of visible and accessible HIV prevention education is necessary.

Distrust:

Respondents expressed a great deal of distrust about HIV information. They do not trust information distributed by the government or by white people. They viewed with suspicion the idea that HIV first spread to humans in Africa. It was a commonly stated belief that the government developed HIV to kill Black people. Many even suspected that they would be infected with HIV if they took an HIV test that involved a needle stick or a finger prick.

Peer Education:

Because of the strong fear and distrust around HIV/AIDS issues, respondents expressed a strong preference for receiving their prevention education information from closely matched peers. This was particularly true for formerly incarcerated men, foreign-born Blacks, and youths. While respondents were evenly split about the importance of the race of the person performing an HIV test, they strongly preferred that their main outreach and education contacts be through closely matched peers. HIV prevention programs should have a strong, peer outreach component.

Confidentiality:

Because of the stigma associated with HIV, community members do not want to be seen getting tested or, in some cases, actively seeking information about HIV. They worry that if they test positive, they will be

required to “go down to the health department and name names.” If HIV+, they would not want anyone to know of their HIV status.

HIV Counseling and Testing:

The stigma and fear associated with HIV is a large barrier to HIV counseling and testing. As mentioned above, many people said they would not want to be seen getting an HIV test because of the implications about their behavior. In general, respondents felt that HIV testing is not easily accessible geographically and that there are many hassles and costs associated with being tested. Because of overwhelming confidentiality issues, they would not want to get tested at a location identified with HIV. They strongly preferred the idea of having HIV testing available in multi-use centers, health screening vans that also screen for diseases other than HIV, or as a routine part of a primary care visit. In a Catch-22, respondents liked the idea of someone from the community performing the HIV test because that would increase their feeling of security and comfort, but they also worried that this might compromise their confidentiality. Professional behavior on the part of the tester was seen as an important indicator of confidentiality.

Leadership:

Many looked to churches and mosques for leadership on HIV/AIDS issues. They felt that religious leaders often helped perpetuate the fear and stigma associated with the disease and would like more positive leadership. They also suggested that they would accept elders and teachers in an HIV leadership role. While civil rights organization were occasionally mentioned as possible leaders, they were not seen as primary leaders on this issue.